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ABSTRACT

In October 1983 Pathfinder, an organization in Minneapolis, Minnesota, was awarded a federal grant to develop a community network model serving children with chronic health conditions and their families. This document describes the model, demonstrated at four sites in Minnesota and Wisconsin. The model is based on four key assumptions: (1) children with chronic health conditions and their families face a common set of problems, regardless of the specific disability; (2) services for these families can be improved by enhancing cooperation among existing health, education, and community programs, rather than by creating new ones; (3) community network building can be best facilitated if the network is initiated at the community level; and (4) community network building for these children and their families will be most effective if the parents are involved in the planning and development of the network. Phase one of the program involves formation of a local task force, catalyzed by the common perception of problems and a shared need to find solutions. The second phase is to determine needs of and resources for children with chronic health conditions. Phase three is the development and implementation of an action plan, setting goals and priorities before planning appropriate strategies. Such strategies include interagency cooperation, parent group development, educational programs, and resource development. The fourth phase is evaluation of the network. Successful collaboration is based on cooperative working relationships between individuals and agencies, a formal needs identification process, leadership development, and realistic funding. (TES)

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MEETING NEEDS WITH SCARCE RESOURCES: COMMUNITY NETWORK BUILDING FOR LOW-INCIDENCE CONDITIONS

Introduction

It is estimated that at least ten percent of all children and youth have a chronic illness or disability. These children and their families have a special set of needs which require the involvement of many agencies and programs in their community. Families must cope with challenges in obtaining appropriate and available services, adequate financing of care, emotional adjustment, changing family dynamics as well as a definition of their place in the community. Such challenges often require the assistance of outside agencies as well as community planning for special services and needs.

Because these children have special needs, the services they require must be obtained from different agencies including the child's primary health care provider, medical specialist, school, county social services, advocacy organizations and other community groups. Fragmentation and duplication can develop, with families caught in the middle. Cooperation among representatives from the key community agencies could be beneficial to the community, family and child.

In October 1983, Pathfinder was awarded a competitive grant from the Division (Bureau) of Maternal and Child Health, Department of Health and Human Services under the category of Special Projects of Regional and National Significance (SPRANS). The grant was awarded to Pathfinder for the development of a community network model for children with chronic health conditions and their families. The demonstration projects were located in the Minnesota communities of Albert Lea and Austin and in Eau Claire, Wisconsin. Specific activities included task force development, community needs assessment implementation, development of an action plan and evaluation of the local network.

The model is based on four key assumptions:

•Children with chronic health conditions and their families face a common set of problems, regardless of the specific condition or disability;

•Services for these children and their families can be improved by enhancing cooperation among existing health, school and community programs, rather than creating new programs;

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•Community network building can be best facilitated if the network is begun at the community level; and

• Community network building for these children and their families will be most effective if parents are involved in network planning and service development.

Pathfinder Community Network

Anyone can initiate a community support network. Interagency collaboration is not a new concept; it has been utilized to plan and deliver services in the health, education, social service and voluntary sector. Pathfinder took this familiar concept and developed a unique model for a specific population: children with chronic illness or disability. Services for these children, especially in rural communities with low incidence conditions, can be fragmented and incomplete. Agencies tend to plan services for these children according to the disability and the current population. Long range planning and systems change rarely occurs.

Pathfinder believes that community service planning and delivery for children with chronic health conditions can occur if this population is perceived to have a common set of problems, regardless of the specific condition or disability. The community can then enhance the current service system to accommodate these special needs. The population, which if identified by disability, seems very small; grouping the children makes the planning effort seem more workable.

The Pathfinder community network model also utilizes the concept that the effort works well if initiated and maintained informally at the community level. The "formal informality" of the local structure us a positive for long range efficacy of the model.

Parents are the key to the Pathfinder community network model. Although it was often difficult to solicit and maintain parent participation, their input was essential in both needs identification and systems planning.

The community network model is firmly based on the belief that flexibility is essential, and each community will develop a unique system to network services. The key is the development of common commitment to the population and a willingness to try something new.

PHASE ONE: Formation Of The Local Task Force

Development of a community network is a structured, consecutive process. Working relationships must be developed among the parties involved and these relationships must be based on mutual respect and understanding. Ultimately, the formation of the local task force is catalyzed by the perception of problems and a shared need to find solutions to those problems.

Pathfinder structured the development of the community network around an outside facilitator; Pathfinder served as the facilitator/consultant for both networks. An outside facilitator can be a valuable asset in providing important feedback to the group and objectively critiquing activities and ideas. This person can be instrumental in bringing the initial group together, coordinating the needs assessment and structuring the action plan.

An initial meeting should be called to bring key participants together. The purpose of this meeting is to help key participants become acquainted and familiarize themselves with other programs and services, to introduce the concept of community network development and to identify common problems. The questions of group mission, purpose and leadership are best dealt with after the needs assessment step.

The main function of leadership in a community network task force is to ensure that the tasks necessary to plan and carry out the group's goals are accomplished. This leadership responsibility may be undertaken by one individual or shared by several members.

Team members usually become more involved and committed to the work of the group when leadership functions are shared by the leader with group members. An Executive Committee, composed of the task force chairperson(s) and subcommittee chairpersons, can function as a governing board for the Task Force.

PHASE TWO: Community Needs Assessment

In order to determine the needs and resources for children with chronic health conditions and their families, the task force must agree on the target population and the geographic area (community).

Definition of Community

A "community" can be defined in many ways. Each professional organization has different geographical boundaries in which it delivers services. Education might have a city-wide school district, public health and social services a county-wide population, and a voluntary organization a multi-county constituency. Each local task force must agree upon a common area for its functioning. In its demonstration projects, Pathfinder defines the community as the geographic area in which FAMILIES receive services, i.e., their health care provider, school, shopping and employment. This allows flexible boundaries which cross traditional catchment areas and reduces turf-guarding among the professionals involved.

Target Population

A definition of the target population also needs to be mutually agreed upon by task force participants. Pathfinder developed the following definition for use in the local demonstration projects in Minnesota and Wisconsin:

A chronic health condition is defined as an illness or disability which necessitates that a child, aged 0-21 years, receive individually planned services for an extended time.

Assessment of Needs and Resources

Once the target population and the community have been defined the first activity of the task force should be to conduct a community assessment of current resources and needs. The format which was used by Pathfinder and developed with the assistance of evaluation consultants is a *key informant approach* to assess current perceptions of resource availability, resource quality and prioritization of needed changes.

PHASE THREE: Development and Implementation of the Action Plan

The community needs assessment will provide the Task Force with a list of needs and resources. The Task Force can then set goals and priorities for action. Planning strategies to accomplish these goals is the next step. Tasks for carrying out the strategies should be clearly defined and assigned to subcommittees composed of persons who have a particular interest or expertise in an issue.

Network Development Strategies

The following are examples of various strategies used by the Pathfinder demonstration projects in Minnesota and Wisconsin. These strategies include:

- Interagency Collaboration
- Parent Group Development
- Educational Programs
- Resource Development

•Interagency Collaboration

Working relationships based on understanding and mutual respect are the basis of a successful network. Issues of territoriality, responsibility, competition and costs are very real and need to be addressed. Pathfinder demonstration project interagency collaboration was based on informal linkages and person/position-based rather than agency-based sharing. Cooperative agreements were not developed; this allowed Pathfinder activities to be viewed as an informal structure which did not add a new agency to the local mix.

Example:

> In one of the southern Minnesota communities, public health nurses (supplying school nurse activities for local school districts), the district special education coordinator, and interested parents worked together to design a school nurse schedule, clarification of the school nurse role and a protocol for management of the student with diabetes.

•Parent Group Development

A parent support group or parent advocacy group may be part of a community network effort. It may be one solution to an area where parents are seeking mutual support or are advocating for services.

Example:

> Parents of children with diabetes and the social services director at the local hospital formed a support group in one of the Pathfinder demonstration projects. The addition of the health professional to the group increased their ability to network with other support groups, provided free meeting space and access to hospital resources, and increased the group's ability to recruit new members.

•Educational Programs

A workshop geared toward health professionals, school personnel, community agency staff and parents is a useful networking tool. Workshops bring people together to share information and ideas. For these reasons, a workshop is also a good way to initiate a network. It can provide an atmosphere for collaboration toward a common goal and a forum to carry it out.

Example:

> Each of the demonstration communities sponsored educational workshops for professionals and parents on issues for families of children with chronic health conditions and the professionals that serve them. The workshops brought together those who were participating in the network demonstration project with other parents and professionals in the region. It also proved to be an effective way to solidify and advertise Pathfinder Task Force activities.

•Resource Development

Collaborative efforts between agencies can produce valuable resources for children with chronic health conditions, their families and the professionals that serve them. The specific resource(s) will depend on the identified need and the resources of the cooperating agencies. With in-kind contributions from individuals/agencies working on the development of the resource, a quality product can be developed with limited funding.

Example:

> Pathfinder, in cooperation with the School Nurse Organization of Minnesota (SNOM), Gillette Children's Hospital and the Minnesota Department of Health developed a manual for those working with children with chronic illness or disability in the school setting. Authors contributed their chapters without

reimbursement and the state health department provided illustrations and printed a limited number of free copies. The manual, *Managing The Student with a Chronic Health Condition: A Practical Guide For School Personnel*, is currently being distributed by Pathfinder for $19.95. Over 1000 copies of the first edition were sold nationally and the Minnesota Department of Health distributed a free manual to each school district and county public health nurse agency in Minnesota.

PHASE FOUR: Evaluation of the Network

An evaluation of the community network process is essential to obtain information on how well the local network functions and whether the group activities have made any impact on children with chronic health conditions. Pathfinder contracted with an outside consultant to independently evaluate community network model development in each of the demonstration projects. The evaluation demonstrated that the local Pathfinder task force had become a "presence" in each community. Task force members felt that Pathfinder activities had been a valuable addition to the community. More importantly, each local group made the decision to continue beyond the funding period of the Pathfinder grant. Each had become a self-sustaining entity in their community structure.

CONCLUSIONS

The development of a community network to improve services for children with chronic health conditions and their families takes planning, commitment, enthusiasm and interest. The key ingredients for the development of a successful network are:

- cooperative working relationships between individuals and agencies;
- a formal needs identification process;
- leadership development in the task force and its subcommittees;
- realistic funding for projects to meet the identified needs; and
- clear and open communication.

A comprehensive description of the process of developing the Pathfinder community networks can be found in the manual, *Guidelines From Pathfinder: How To Develop A Community Network*. The manual contains general principles as well as a step-by-step process for creating a network in any community. *Guidelines from Pathfinder* is available from Pathfinder at the above address.